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Some people with disabilities have been isolated in their care homes for months. Experts say it could lead to an 'avalanche' of mental-health issues

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Pamela Libralesso spends time with her 14-year-old son at their home in Barrie on Sept. 2, 2020.

TIJANA MARTIN/THE GLOBE AND MAIL

The effect of six months of separation became apparent when Pamela Libralesso and her husband were reunited with their 14-year-old son in late August.

When the mother from Barrie, Ont., saw him at his residential care home for the first time since early spring, she reached out to take his hand – but he quickly pushed it away. The “extremely happy and affectionate” teenager, who usually would be cuddling and climbing all over his dad, was withdrawn.

“He is 100-per-cent a daddy’s boy, and for him to completely ignore him the way he did was concerning,” said Mrs. Libralesso.

Her son, who has intellectual and developmental disabilities, lives full-time in a group home where he receives 24-hour-a-day care. Before the pandemic, Mrs. Libralesso would bring him home overnight most weekends and visit him throughout the week. But in early March, his group home restricted visitors because of COVID-19.

Eventually, the group home allowed physically distanced visits, but Mrs. Libralesso explained that since her son is non-speaking and communicates through touch, a distanced visit would be “frustrating beyond belief” for him. To prevent him from running up to them, he would have to stand behind a barrier or be restrained. She feared it would do more harm than good – so she made the difficult decision not to visit while distancing was in place.

“He could not communicate in the way that he communicates,” said Mrs. Libralesso.

In the last week of August, provincial restrictions began to be lifted on visits and outings for people in group settings, enabling residents to see family and leave their homes – some for the first time in months. For some of these residents, the separation and isolation has caused deep mental and emotional distress, which some experts say will be a challenge to navigate without support from the province and care agencies.

And some are still waiting for the opportunity to leave their homes.

Kathy Vainai, a 34-year-old woman with Down syndrome who lives in a group home in Toronto, says that before the pandemic, she was used to seeing her family, friends and boyfriend. “I could go out on my own,” she said. “I could hang out with my friends. I could go to movies. I could hang with my sister.”

But the COVID-19 restrictions brought her usually independent life to a halt. Starting in April, she was not able to leave the premises.

Nearly a week after the provincial restrictions on outings were lifted, she was still waiting for the managers of her group home to determine when she can safely leave.

"I can't leave the house. I'm always at home," she said in a phone call from her group home in early September. "The only thing we're allowed to do is go in the backyard, take a walk, and that's it. I feel trapped."

In April, the Ontario government released its COVID-19 Action Plan for Vulnerable People, which recommended limits on visitors deemed "non-essential" in congregate living settings – a range of facilities where people live or stay overnight and use shared space. The safety measures also included no overnight visits and no outings where distancing could not be achieved.

As the pandemic wears on, Ontario's guidelines have gradually been loosened. Restrictions on outdoor visits began to be lifted on June 12; on July 22, some physically distanced indoor visitors were permitted. In early September, restrictions were lifted on outings and short-stay absences.

Empower Simcoe, a non-profit organization that manages 41 homes for people with intellectual disabilities – including the one in which Mrs. Libralesso's son resides – says their guidelines on visits and activities have evolved alongside the provincial ones.

"Our responsibility has been to practise due diligence in preventing the spread of COVID-19 into our congregate-care settings, while ensuring the health and safety of the people we support, and of the essential front-line workers who care for them," said CEO Claudine Cousins. "We have not had any cases to date."

Pamela Libralesso and her family were unable to visit their son at his group home for six months due to restrictions.

TIJANA MARTIN/THE GLOBE AND MAIL

However, advocates note that the province's guidelines leave many decisions up to individual agencies, including which safety protocols will be followed and how they'll balance the safety of residents with their individual needs.

Even distanced visits have been stressful on some group-home residents. Starting in July, Karina Zwaan was allowed to see her daughter, Allyson Zwaan-Fragomeni, during distanced visits at her Empower Simcoe group home. When restrictions were especially strict, they could only visit outdoors, separated by a chain-link fence, with no touching or hugging. In an interview in August, Ms. Zwaan said that for Allyson, who has developmental disabilities, it wasn't clear why the new rules were in place.

"We're used to seeing this really active, vibrant 25-year-old woman who loves to hug and play and run around and chase us, and now she's just kind of cautious," said Ms. Zwaan. "In my opinion, I feel like she's thinking she's done something wrong or something to upset us."

Sue Hutton, a program co-ordinator at ARCH Disability Law Centre, says her office has heard many reports of "really serious mental-health outcomes for people with intellectual disabilities."

Ms. Hutton says there must be adequate staffing levels within congregate-care homes, as well as education for staff on how to recognize and support mental-health issues. "Otherwise, I really see us looking at a huge avalanche of mental-health issues coming out of this that aren't being addressed."

The shock of the sudden isolation may have had a traumatic impact on some people with intellectual and developmental disabilities, says Dr. Yona Lunsky, director of the Azrieli Adult

Neurodevelopmental Centre at the Centre for Addiction and Mental Health in Toronto. That trauma might also be difficult to identify, because some people with disabilities might not communicate their trauma in a way that may be familiar to caregivers, she says.

Dr. Lunsky says that helping people with disabilities and their caregivers navigate through the impact of this trauma should be a priority for congregate-care agencies and the province. "How do we help people with disabilities deal with trauma? How do we help families, and how can we offer trauma-informed care in the steps we take next?" said Dr. Lunsky. "We can't expect anyone to suddenly know."

But as restrictions begin to ease, there are growing fears from advocates that lockdowns will happen all over again with a possible second wave.

NDP MPP Lisa Gretzky tabled a motion in the legislature in July asking the Ontario government to develop a strategy to ensure a "complete lockdown" doesn't happen again.

Other people have taken to the legal system. In June, Mrs. Libralesso filed an application on behalf of her son with the Human Rights Tribunal of Ontario against Empower Simcoe. She claims the restrictions on visits have had a detrimental effect on his mental health and well-being, and has decided to continue with the application despite the loosened guidelines – to fight for other families and prevent another lockdown.

"No child should be separated from their family for six months for any reason," she said. "There are several families that are still not in a good place. And until everything is resolved for every family, I'm not done."

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